Empowering parents!

 Experiences from parent-focused interventions in groups and online using the AKKtiv ComAlong early communication intervention

> Gunilla Thunberg, Dart centre för AAC and AT, Sahlgrenska University Hospital And Department of neuroscience and physiology at Sahlgrenska Academy, University of Gothenburg







My inspiration, Alfred 29, autism and ID









Today's presentation

- Background AKKtiv
- ComAlong group intervention and research results
- ComAlong online intervention and pilot study
- Pilot investigation of ComAlong online, new research and some problems.....





Background AKKtiv = AAC Early intervention ComAlong group

- My doctoral project: filming 4 families almost a year – it isn't easy to be a parent of a child with communication problems, autism and to use AACaugmentative and alternative communication in your home! Something is needed!
- There is evidence of what works for young children who have problems with communication and languagestronger and stronger evidence base!



Evidence-triad early communication intervention

1. Parents/partners have to lern responsive communication strategies – break the negative circle that start early on meaning that we are to directive and take over.

2. Environmental milieu teaching. Strategies used by the parents and other partners in the natural daily context of the child and in play





- Manual signing
- Pictures -
- Speech output devices/apps also camera/video on smartphones
 To provide rich augmented input!
 Support communication and language building – stimulate speech!



ComAlong group

- Led by 2 professionals, 1 speech therapist main responsibility
- 5-12 families, both parents if possible.....
- 7 sessions / 2 hours
- Theory discussion based
- Practise exercises, AAC breaks
- Film clips
- Videos from 2 families/session
- AAC tools to bring home
- In-between exercises





ComAlong themes

- Communication
- Communication development
- Partner strategies
- Play and communication
- AAC in daily life
- AAC workshop
- Communicative rights summing up Optional:

Play-get-together with children





Research results – mainly interview studies and surveys

- Highly appreciated: 8,6 on a scale from 1-10
 - Independent of gender, educational background, diagnosis of the child BUT
 - Parents of children with PIMD multidisabled work better as a separate group
 - Parents of younger children a bit more positive
- The vast majority of parents state that they change their communication with the child: wait longer, slower, use AAC more
- They also state the communication of the child is affected: initiates more, use AAC, talks more, more interested in contact
- The best: Meeting the others! Empowering!

List of published articles:

https://www.akktiv.se/publikationer/





Also some unpublished quantitative results

- Improved social life less negative impact
- **FIQ submitted**



• Increased development of communication and language

CDI, VABS



So – why an online resource when our group interventions are working so well?





The situation right now in many parts of Sweden...

- Well aware of the importance of identifying children with communicative difficulties early in order to intervene, affect development, family situation and participation. Many will be diagnosed with autism and other neuropyschiatric disorders – and some with ID.
- We are good at screening- many children are identified at 2,5 years
- **But** resources are insufficient......children are placed on waiting lists; first for investigation and assessment at speech-language pathology or neuropsychiatric clinics.....and then to wait for intervention......





Idea ComAlong online

- Provide evidence based knowledge using digital technology – independent of access to professionals and time (both for clinics and parents)
- Support and complement to other interventions – aim has not been to replace existing resources!
- Existing research of digital intervention positive, however better results with access to guidance/personal expertise





Development project

- Large network of stakeholders in West Gotaland.
- Financial support from central administration
- Different groups providing input: management repr, clinicians, researchers
- Group of developers at Dart, specialists on early communication intervention (akktiv.se)



Resource on 1177- national platform for health care - released feb 2022

- Digital resource aimed at parents of children with communication difficulties
- An intervention being part of the *AKKtiv*-program based on the three pillars of early intervention (1) responsive communication, (2) environmental milieu teaching strategies, (3) augmentative and alternative communication.
- Texted information, animations, video clips, material to download, pods: experts and parents

11777 vårdguiden



Examples

- Animated educational clip
- Video clip: parent using AAC (model)





Pilot study – mixed methods

- Survey before-after intervention
 - 3 parts: child interaction, family social life, evaluation of intervention
 - Descripitive statistics
 - Non-parametric tests regarding potential significant change
- Individual semistructured interviews thematically analyzed
- Integration using triangulation
- Full data from 8 parents test period of 8 weeks (shorter than clinical use)





Result thematical analysis

• Relevance of content

Main theme: *ComAlong online – a rewarding intervention*

Themes:

- Relevance of content
- New insights and widened knowledge
- Suggestions of content

"I have opened my eyes to his communication. Things I did not think of before as communication have become more clear to me – yes, yes, of course this is also communication" (6)



Result thematical analysis

Main theme: *Functional and flexible*

Sub themes:

- User friendliness
- Aspects of online use
- Composition of content
- *Time aspects*

"it's a fantastic resource for like people just standing in the queue. Right now you completely lack back-up or just something to do, youre just left to yourself" (1)(6)

Result thematical analysis



Huvudtema: New perspectives on interaction and communication

Underteman:

- Change in parents' interaction
- Child response
- AAC use

"Now we like have a day schedule put on our fridge of what are we going to do? Yes but when we wake up we will walk straight to the fridge, then to the WC, brusch your teeth, like this all the things to do(3)

Survey results

- interaction with child: Some significant changes
- impact on social life. No significant change.
- Evaluation part *ComAlong online*: M= 3,3 4,9 (5 max)
- Overall score of *ComAlong online* M=8,91 (10 max).

-Some parents had not gone through all material.







Discussion & conclusions from this pilot

• 1. *How did parents perceive ComAlong online?* ComAlong online was perceived as positive, instructive and easily accessible. An online intervention provided flexibility. BUT - the opportunity to ask questions to caregivers and have contact with other parents was requested.

2. *Did parents perceive change in their own communication?* Parents reported change in their communication: i.a. increased use of pictorial support, increased responsive communication and started planning the use of AAC.

3. Did parents perceive any change in their child's communication? Yes!: Increased eye contact, increased initiative for communication, increased interest in pictures & signs. Some children imitated & vocalized more and one child had started to use more words / syntax. In some children, no changes were seen. Significant increase in pointing to objects in survey responses.

AKK

What happens now?

- Slow implementation......the national platform is crowded with new digital interventions
- Nurses who will prescribe ComAlong online have to take a half-day-course – takes time
- Nurses not always positive feeling this should be the job of the speech therapist.
- Many/some? parents have difficulties getting started and going through the resource.....
- But NOW it seems like we're rollin!



 We now collect data to compare results from the group ComAlong+online versus ComAlong online only – what are the differences? Different parents? Children? Social situations?

Thankyou for listening! Gunilla.Thunberg@vgregion.se



Please contact me for further information







www.akktiv.se